## The Millennium Series in Women's Health

# Identifying and Caring for Underserved Populations: Experience of the National Centers of Excellence in Women's Health

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#### ABSTRACT

From 1996 through 1998, 18 National Centers of Excellence in Women's Health (CoEs) were designated by the Office on Women's Health (OWH) of the U.S. Department of Health and Human Services (DHHS). These CoEs were charged with developing standards for comprehensive, multidisciplinary, and culturally competent approaches to women's health. One specific mandate to the CoEs was to address the needs of underserved women. This paper presents the efforts of the CoE Racial and Ethnic Minority and Underserved Women Working Group to describe the work done within the CoEs to meet this mandate. One method of defining underserved populations is the seven-point definition used in the current "Index for Primary Care Shortage," which categorizes underserved populations based on characteristics including race, ethnicity, geography, and health outcomes. The definition allows the local identification of underserved communities based on this group of variables. The analysis included in this paper focuses specifically on the CoEs' efforts to operationalize this definition in order to meet the clinical care needs of women who are of low socioeconomic status (SES), racial or ethnic minorities, or non-English speaking. A brief review of the literature linking these characteristics to being underserved is provided, followed by examples of ongoing activities at the 15 currently funded CoEs, to understand the needs of diverse women, to improve the quality of care provided to women, and to address healthcare needs of underserved women who meet this definition. Efforts to serve three additional underserved populations defined by age, sexual orientation, and disability status are also presented.

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## **INTRODUCTION**

IN OCTOBER 1996, the Department of Health and Human Services (DHHS) announced the establishment of 6 National Centers of Excellence in Women's Health (CoEs).1 One year later, 6 additional CoEs were established,<sup>2</sup> and the final 6 were added in 1998.<sup>3</sup> In total, 18 centers were established although only 15 remained funded in 2001. The charge of the national CoE program was "to establish and evaluate a new model healthcare system that unites women's health research, medical training, clinical care, public health education, community outreach, and the promotion of women in health professions around a common mission—to improve the health status of diverse women across the life span."4 The overall goal was to establish standards of excellence for a comprehensive, multidisciplinary, and culturally competent approach to women's health.<sup>5</sup> Supporting the national funding for the CoE program was a belief that women's health needs were not being met by the healthcare system and that transformative change was necessary to improve overall women's health. The CoEs were expected to develop models that were responsive to the needs of their communities, institutions, and historical strengths and weaknesses.

One specific mandate to the CoEs was to address the needs of underserved populations. Traditionally, underserved populations are defined as groups whose demographic, geographic, or economic characteristics impede or prevent their access to healthcare services. This paper presents the work of the CoE Racial and Ethnic Minority and Underserved Women Working Group to operationalize the definition of underserved women and describe the work done within the CoEs to meet this mandate.

## UNDERSERVED POPULATIONS

The federal definition for being medically underserved provided the base from which the CoE focus was developed. Currently the "Index for Primary Care Shortage" (IPCS) is used to define medically underserved populations [Designation of Medically Underserved Populations and Health Professional Shortage Areas. Federal Register 42 CFR Parts 5 and 51C, Part V, September 1, 1998]. The IPCS is a composite of seven variables: (1)

the population/primary care practitioner ratio, (2) the percentage of the population with incomes below 200% of poverty, (3) the infant mortality or low birth rate, (4) the percentage of the population that is racial minority, (5) the percentage of the population of Hispanic ethnicity, (6) the percentage of the population that is linguistically isolated, and (7) low population density. Behind these criteria are the assumptions that (1) primary care is important, (2) there is a relationship between socioeconomic status (SES) and care, (3) outcomes of pregnancy are a good marker of community health, (4) there is a relationship between race and health, (5) there is a relationship between ethnicity and health, (6) non-English speakers experience barriers, and (7) geography is important in accessing care. A review of the current healthcare literature confirms these assumptions, although they are viewed as insufficient to explain the full range of inequalities in health.

Using the IPCS criteria and the assumptions behind them, the CoE Racial and Ethnic Minority and Underserved Women Working Group sought to develop a criterion for categorizing the work being undertaken by the CoEs to address the needs of underserved women. This analysis focuses on efforts by the CoEs to meet the clinical care needs of underserved women who are of low SES, racial or ethnic minorities, or non-English speaking. CoE efforts to address the inclusion of underserved women in research, <sup>8,9</sup> professional education, leadership development, <sup>10</sup> and community outreach <sup>11</sup> are discussed elsewhere.

# WHO ARE THE UNDERSERVED WOMEN?

The axes of oppression for women are overlapping and interactional and include but are not limited to gender, race, ethnicity, SES, sexual orientation, and age. For each of these areas, a substantial body of literature exists that seeks to explain the mechanism of action between the variable and health inequalities. For the purposes of this paper, a brief overview of that literature is provided. The authors acknowledge, however, that each of these fields of exploration is rich and complex and cannot be adequately addressed within the limitations of this paper. Given that caveat, we seek to ground the reader in a cursory understanding of the axes of oppression and their

impact on women's health. Following that review, examples are given of current CoE efforts to meet the needs of women who are currently at risk for poorer health outcomes.

#### SES and health

A growing body of evidence has demonstrated that SES is a strong predictor of health. 12-18 An inverse association between SES and mortality has been documented in almost all countries where the association has been examined. 14,15 The relationship between SES and health occurs at every socioeconomic level and for a broad range of SES indicators and cannot be accounted for simply by classic risk factors, such as diet and smoking. 12,15,19 As documented by a considerable body of research, no single factor accounts for links between socioeconomic position and health. Instead, numerous investigators have delineated a myriad of interconnected pathways whereby people's health is harmed or helped by their standard of living, workplace conditions, and social and psychological interactions with others at home, work, and other public settings. 14,17,20-27 The effects of SES on health have been modeled in various ways. Feinleib and Ingster explain:

One is that income grants access to good housing and healthier environments, reduces exposure to social stresses such as high crime rates, unemployment, and residential and marital instability; provides access to medical care and other amenities . . . ; and presumably conveys more desirable working conditions. Another SES indicator of health is occupation, which controls exposure to physically toxic or stressful environments and can offer related rewards. . . . Finally education influences health behaviors, value structures, and problem-solving abilities. . . . Obviously these three factors overlap, although studies have found that the correlation among them is low, indicating that these indices of social class are not interchangeable, and they measure different facets of social class.<sup>28</sup>

Defining and understanding each of these indices are especially problematic for women. 18,29 Research has not yet determined how best to define a married woman's social class in relationship to the social class of her husband, what the relationship is between an unmarried woman's social class and the social class of her parents, or how to classify the social class of divorcees or widowed women. 28 Despite the imprecise nature

of these indices, however, researchers argue that economic structural relationships, abbreviated as "years of education," "usual occupation," or "family income," play a major role in shaping women's health.<sup>30</sup> Women with more education and higher income live longer than women with fewer years of schooling and less income, and they are healthier along the way.<sup>30</sup> Irrespective of race, women who are poor or near poor are far more likely to describe themselves in fair or poor health than are women with middle or higher incomes.<sup>30</sup> A woman's chance of getting medical care depends on her employment and marital status, and she is often disadvantaged compared with a comparably situated man.<sup>31</sup>

Poverty is intrinsically entwined with gender and ethnicity and race as well as with marital status and household configuration.<sup>23</sup> SES, however, is not simply an individual level factor. Current work on SES has found that communities with lower average levels of income, education, and other such factors have higher rates of morbidity and mortality than communities with higher socioeconomic levels.32 Thus, conceptualizing and testing the complex relationships among race, racial segregation, community and individual socioeconomic position, and health are important but extremely difficult.<sup>33</sup> This conceptualization is compounded for women whose relationship to community level factors may differ from that of men.

The authors of this paper, therefore, recognize the inherent difficulty in operationalizing low SES in a way that can be used to understand the work of the CoEs. The CoEs do not claim to understand the unique impact of their services across these independent indices. Instead, the CoE Racial and Ethnic Minority and Underserved Women Working Group selected a proxy marker for SES, insurance status, and used it as a means of understanding their work. Although the authors recognize that this marker is imprecise and underdeveloped, other more routine markers, such as income, education, and occupation of patients, are not routinely available. Prior work, however, has demonstrated that each of the SES indices of interest-education, occupation, and income—affect access to health insurance.<sup>34</sup> An example of the impact of insurance status on women's health was documented in a recent study looking at use of anesthesia in labor for women with public and private insurance. Mothers delivering vaginally under Medicaid, HMO,

or no coverage had significantly lower odds of receiving epidural anesthesia compared with those under traditional private insurance. Although there were some differences by race, the strongest determinant of anesthesia remained insurance type.<sup>35</sup>

## Race and ethnicity and health

Despite the robust nature of SES as a marker for health status, it is not sufficient to explain disparities in health outcomes. Research has found that adjustment for SES substantially reduced but did not eliminate racial disparities in health, 13,23,36–40 and race has been shown to be independent of SES as a risk factor for poorer health outcomes. 41,42 Studies have suggested that these racial differences in outcome are more pronounced for women than for men. 43,44 Because of the complex intertwining of race and SES, work to address health disparities must consider both factors. 33

Although race is routinely used to describe a category of people, it is recognized that race is not a biological concept but rather a social one. 45,46 Accordingly, race is a socially constructed taxonomy that is based on an ideology of limited biological significance.<sup>42</sup> Race is better understood as a dimension of social experience, as race denotes relations between people and not substantial qualities possessed by them.<sup>47</sup> Racialization, or the construction of race, is a contested process of ordered social relations.<sup>48</sup> Race can be understood largely as a measure of exposure to health risks<sup>49</sup> and as a gross indicator of histories and specific conditions of life that bear on access to health services and patterns of medical care utilization.50

The role of race in determining the health status of Americans was made clear in 1985 in the now famous Report of the Secretary's Task Force on Black and Minority Heath.<sup>51</sup> The summary of that multivolume work highlighted that the health status of minorities in the United States was disproportionately lower than that of whites. Since that time, an entire body of literature has been produced, including both government documents and independent scientific studies, on the race-based differences in health status among the U.S. population.<sup>52</sup> Disparities in healthcare have been linked to such differences in outcomes in numerous studies, 53-60 and recent studies on care for heart disease have demonstrated these differences,61,62 especially for women.63-65

Race and ethnicity continue to be discussed as interchangeable terms,66 although scholars of these issues support a separation and explication of the terms, 67 arguing that although there is overlap, race and ethnicity are not one and the same. 49 Ethnicity is important in understanding the inadequacy of current models of discrimination to explain all social inequalities. 68 The concept of ethnicity is neither simple nor precise, but it implies one or more of the following: shared origins or social background, shared culture and traditions that lead to a sense of identity and group, and a common language or religious tradition.67 The term "ethnicity" refers to all such traditions, customs, activities, beliefs, and practices that pertain to a particular group of people who see themselves and are seen by others as having a specific sociocultural identity.69 Researchers concerned about women's health have begun to focus on the role of ethnicity in health. However, self-assessed ethnicity is changeable over short periods and not subject to control in measurement. 67 To address this, investigators have sought to understand the role of acculturation in health outcomes. Although they acknowledge "acculturation as one of the most important predictive factors in both health access and health status measures,"70 they also point to its problematic nature because of the "assumption that acculturation is a static process that can be captured and measured by specific attributes such as language, ancestry, behaviors, and attitudinal preferences."70

## Role of race and ethnicity in health outcomes

Racial and ethnic groups in the United States continue to experience major disparities in health status. Compared with non-Latino white populations, racial and ethnic minorities bear a disproportionate burden of mortality and morbidity across a wide range of health conditions. <sup>23,34,71–73</sup> Within each level of SES, African Americans generally have worse health status than whites. <sup>13,52</sup> Infant mortality rates, considered one of the most sensitive indicators of the health and well-being of a population, <sup>74</sup> are twice as high among African American infants as whites, even when controlling for measures of SES, such as mother's level of education. <sup>75</sup>

Disparities in health status are compounded by reduced access to healthcare services.<sup>34</sup> Race and ethnicity are particularly important in understanding access to preventive and primary care.

In 1996, 30% of Latinos, 20% of African Americans, and 16% of whites did not have a usual source of medical care. 75 Since 1997, the gap between Latinos and whites with no usual source of care has widened.<sup>75</sup> Although many factors affect health status, the lack of health insurance and other barriers to obtaining health services diminish the use by racial and ethnic minorities of preventive health services and medical treatments that could reduce disease and contribute to improved health status.<sup>34</sup> For example, elderly African American women are still less likely to have had a mammogram than their white peers despite reimbursement for the service,41 and Hispanic women are also less likely to be screened for breast cancer than white women.<sup>76</sup>

Although the Latina population exhibits many classic risk factors (including low income, education, and access to care), they generally exhibit good birth outcomes. Previous work has deemed this finding the "epidemiological paradox."77-80 Unfortunately, this generally positive profile must be contrasted with high levels of chronic morbidity and mortality later in life, resulting from preventable or controllable diseases. The epidemiological paradox may evaporate as the population ages because of lack of access to preventive and treatment services for these chronic diseases.81 Variations in health status are also remarkably different for subpopulations of Hispanics. Research has demonstrated that risk factors for morbidity and mortality vary among Mexican American, Puerto Rican, Cuban American, Central or South American, and "other" Hispanics subgroups.<sup>81</sup> For example, in 1993, rates of low birth weight were 5.9% among non-Latino whites, 13.4% among non-Latino blacks, and 6.2% among Latinos in general, but 9.2% among Puerto Ricans.82 Such disparities highlight the need for increased commitment to adequately identifying and quantifying health outcomes for Hispanic subgroups.83

The categorization of Asian American and Pacific Islanders (AAPI) has been constructed so as to form a "model minority," allowing policymakers and public agencies to view AAPI as a single homogeneous community that lacks serious health or social problems. The AAPI population, however, comprises more than 40 distinct ethnic populations, with large variations in national origin, language, culture, socioeconomic profile, immigration experiences, and levels of acculturation. Bipolar distribution of rates among AAPI subpopulations often results in deceptive

median rates, creating a picture that erases the poor health outcomes of many subpopulations within this broad racial category. For example, in California, among Asian women in aggregate, approximately 7% deliver low birth weight babies compared with 12% of African American women. However, when subpopulation disaggregation is taken into account, startling differences are identified: U.S.-born Southeast Asian women have a low birth weight figure identical to that of African American women at 12%.84 Similarly, rates of poverty are divergent across AAPI subpopulations. Currently, Southeast Asian poverty rates in California are among the highest in the nation. In 1989, 35% of foreign-born Southeast Asians living in California had incomes below the poverty line.84 Therefore, attention must be paid to analysis of health outcomes of AAPI subpopulations.

Linguistic isolation may exacerbate the needs of racially and ethnically defined populations. Language has a direct and powerful relationship with health outcomes.<sup>85</sup> Numerous studies have examined the impact of language on access to appropriate healthcare services, specifically as a result of language discordance between providers and patients.<sup>86,87</sup> Language also appears to be an independent predictor of access to health insurance.<sup>88</sup>

#### CoE ACTIVITIES

Historically, women's healthcare has been characterized by fragmentation, largely caused by the separation of reproductive healthcare from other clinical care services for women.89 One of the core functions of the national CoEs is the development of models of comprehensive, integrated clinical care services for women. The CoE agenda is ambitious. It calls for major transformations in the conceptualizing and practice of women's health, including the development of a one-stop shopping model to overcome the fragmentation in services among internal medicine, family practice, obstetrics/gynecology, specialty care, and other health education and support services. The goal of the CoE is to make gender-specific and gender-sensitive services available to all women across the life-span.<sup>5</sup> The examples we give of CoE activities demonstrate the extent to which efforts to meet this goal have been targeted at underserved women. One of the strengths of the CoE program is the support for individual

centers to develop organic approaches to meeting the needs of specific populations of women.

Currently, there are 15 funded national CoEs at Boston University; University of California, Los Angeles (UCLA); University of California, San Francisco (UCSF); Harvard University; University of Illinois at Chicago; Indiana University; Magee-Women's Hospital; MCP Hahnemann University; University of Michigan; University of Pennsylvania; University of Puerto Rico; Tulane/Xavier Universities; Wake Forest University; University of Washington, Seattle; and University of Wisconsin, Madison.

## Research on the needs of diverse women

To better understand the gender-specific primary care needs of women, focus groups were held at 6 CoEs (UCSF, Magee, Pennsylvania, Boston, Michigan, and Wake Forest) with women of diverse age, SES, and geographical residence for each of the following populations of women: African American, Chinese (Mandarin-speaking), Hispanic/Latina (both English-speaking and Spanish-speaking), white, and lesbian. The objective was to conduct the formative work necessary to develop a set of patient satisfaction items based on women's needs and perspectives. Each of the participating centers conducted at least 3 focus groups for a total of 23 groups with 193 participants. Community residents, rather than CoE patients, were selected in order to ensure a variety of healthcare experiences and to include women who do not have access to healthcare.90 The groups were conducted by female facilitators using a focused discussion guide. Women were asked to discuss the meaning of "women's health" as well as their experiences with accessing healthcare, checking in at the appointment, provider/patient interactions during the visit, other sources of care used, checking out, and follow-up care. In general, participants in all groups defined "women's health" as including both reproductive and nonreproductive aspects of health. Several issues specific to racial and ethnic groups were identified in the focus groups. For example, African American women were more likely than other women to identify trust in their providers as a key issue in their healthcare. Asian women raised the importance of quality of care defined by expertise and cost. Women of low SES and Medicaid enrollees were more likely than other women to identify basic access to services

as a key issue. Overall, there were marked similarities across groups in preferences for good communication with providers, comprehensiveness of care, and privacy and comfort.<sup>90</sup>

The results of these focus groups have been used to inform the clinical care delivery system at all CoEs as well as to develop a women's patient satisfaction survey. 90 The tool has been field-tested and is now being used to assess satisfaction with care for the currently funded 15 CoEs. In addition to patient satisfaction data, quality of care also is being measured at these sites. The results of these two data sources will be compared to nationally available data of women's health-care.

## Access to the CoE model

Weisman and Squires<sup>91</sup> conducted an analysis of the clinical centers of the first 12 national CoEs. They compared the CoEs to a sample of 56 hospital-based, primary care, women's health centers identified in the 1994 National Survey of Women's Health Centers, the only source of nationally representative data on primary care women's health centers. 91 The study found that the CoEs were more likely than the centers from the national sample to operate multiple sites, a marker for expanded access across geographical locations. All CoEs employed at least two types of primary care physicians, typically internists and obstetrician/gynecologists, compared with 39% of the national sample. The most striking result of the study was found in the characteristics of the patient population served. The patient populations of the CoEs included proportionally more nonwhite patients and Medicare recipients than the national sample. On average, 51% of women served by the CoEs are nonwhite compared with 30% in the national sample, and 18% of the COE patients are Medicare recipients compared with 11% of the national sample. Both of these results were statistically significant. The CoEs also demonstrated a statistically significant difference in the core values of the programs that, in addition to providing clinical care, emphasize research, education, training, and a commitment to women's reproductive rights.<sup>91</sup>

One example of how multiple sites represent the expanded accessibility of the CoE program is the Living Water Prenatal Care Center that was established by the Wake Forest University CoE to provide services to low-income women in the southeast quadrant of Winston-Salem, North Carolina. The program was developed after a church consortium opened an NC Smart Start Program (similar to the federal Head Start) in the basement of an underused church building and the program director noticed that the parents of the children needed basic healthcare. The church consortium invited Wake Forest to open a prenatal care clinic, and the university provided resources for renovating and staffing. Currently, the clinic provides breast and prenatal care and direct referrals for other medical care if needed. The clinic is for low-income women in the church's multiethnic surrounding community. Healthcare is provided at low cost or no cost to community members, and Spanish language interpretation is available. The Living Water Clinic is also part of a church coalition that provides a pharmacy fund to help patients purchase medications. Since the clinic's beginning, there has been a steady increase in the number of people served, and currently over 150 women are seen each month.

## Improved quality of care

Another investigation of the CoE model of comprehensive women's healthcare demonstrated that, overall, women are likely to have better coordination of preventive healthcare with this model of care than with traditional internal medicine practice.92 For the study, 3025 female patients were randomly selected to receive a mailed survey after their office visit to a women's health center or an internal medicine practice at each of three university-affiliated teaching hospitals, Boston Medical Center, Brigham Women's Hospital, and Massachusetts General Hospital. The survey asked patient characteristics, patient satisfaction, and rates of gender-specific preventive health services. After adjusting for measured differences in patient characteristics and site, patients at women's health centers were more likely to receive their gender-specific preventive health services from their primary care provider, including breast examinations, Pap smears, hormone replacement therapy (HRT) counseling, and dietary calcium discussion. These findings remained when the analyses were limited to patients of female providers only. As discussed earlier, minority women and women or lower SES often have lower use of preventive health services. Thus, access to models of care

with higher provision of the needed services is likely to directly benefit underserved women.

Currently, the 15 funded CoEs are undergoing a quantitative evaluation to assess patient satisfaction and quality of care. Two hundred patients at each of the CoEs will be surveyed by trained telephone interviewers using a computer-aided telephone interviewing system.<sup>93</sup> This study will address whether underserved women are receiving quality care. Additionally, the Harvard Medical School Fund for Women's Health granted an award to study the "Impact of 'One-Stop' Comprehensive Care on the Quality of Care for Minority Women," which should provide additional information on the effect of the CoE model on the health of underserved women. Results from these two studies will provide evidence of the ability or inability of the CoEs to meet the needs of underserved women.

Addressing the health needs of racial and ethnic minority women

CoE efforts to address underserved racial or ethnic minorities generally focus on three populations: African American, Hispanic/Latina, and AAPI, although many projects address the issues of women of color broadly defined. For example, health diaries are a mechanism by which individuals can gain information necessary to promote good health as well as track their personal health history. The Harvard University CoE has developed a "Minority Women's Health Diary" that women can maintain throughout their lifetimes, from adolescence to older age. The diary focuses on the needs identified by minority women and is available in several languages. The diary is divided into sections according to age categories, and each section provides a general description of what should take place in a standard examination with a medical provider and suggested questions to ask the healthcare provider. The sections also contain information about major health concerns for each age group, with explanations about preventive strategies and treatment options. Accompanying written and video health education materials can be used with or without the diaries.

Addressing the health needs of African American women has been a priority for several of the CoEs. The Indiana University CoE, for example, sponsored the Indiana Black Expo Fair, which addressed such topics as domestic violence, sexu-

ally transmitted diseases (STDs), HIV education and screening, family planning, osteoporosis, smoking cessation, and exercise. Magee-Women's Hospital CoE supports the African American Womencare Program, which plans educational events for African American women in the community, such as the African American Women's Health Wellness Day, and publishes an African American Womancare Newsletter. The University of Illinois CoE launched the Roseland Project to increase physical activity among middle-to-older aged African American women in the Roseland community area.

The University of Pennsylvania CoE has developed the Health Tip Card Project, an educational outreach activity that is socially and culturally specific to African American women. These easy-to-read cards with large, beautiful pictures cover such topics as cardiovascular disease, depression, cancer, and female aging issues. Two themes are prevalent in the cards: What you need to know and What you can do. The Tip Cards emphasize the role women can take to ensure healthy lifestyles and include a list of community resources as well as a heart healthy recipe. In 2000, the creators of the Card received national recognition for the project from Tipper Gore, wife of the former vice president.

The greatest efforts to meet the needs of the Latina population are being undertaken by the Pueto Rico CoE. Using multiple strategies, the Puerto Rico CoE is expanding access to care and education for the women in Puerto Rico. Also, because it is a member of the CoE program, the unique needs of this population are highlighted for the remaining 14 CoEs. In addition to providing direct care, the Puerto Rico CoE disseminates educational materials and newsletters to partner organizations. It has developed a conference room on wheels, which can travel to off-site locations to provide educational programs to local communities.

Both the UCLA CoE and the Wisconsin CoE websites features patient education resources in Spanish. The UCLA lends Spanish-language videos free of charge from its resource center. The Wake Forest University CoE has developed a health guide for use by older Hispanic adults. This guide includes bilingual information on women's healthcare that can be used to facilitate care between language discordant patients and providers. A place to track healthcare results and

a care-planning map are also included. The Consortium for Latino Health, in which the MCP Hahnemann University CoE participates, is a member organization of healthcare and various community organizations that are concerned about the Latino community's access to healthcare.

The University of Michigan CoE hosted an Asian American Women's Health Conference that offered lectures and literature on health issues specific to Asian women. In collaboration with investigators at Wake Forest and community-based partners, the UCSF CoE has translated and modified the Wake Forest University CoE health guide for Hispanic older women to be appropriate for use with the Chinese community. The UCSF CoE has used the results of focus groups with Mandarin-speaking women to adapt clinical services to meet the needs of Asian American women, which comprise almost one third of the San Francisco population.

Several CoEs have also sought to address linguistic isolation within the white population. For example, more than half a million people from the republics of the former Soviet Union immigrated to the United States during the last two decades, and many of these new immigrants do not read or speak English. Although they are categorized as white, they experience linguistic isolation and thus remain underserved by the healthcare system.94-97 The UCSF CoE has worked to understand and to meet the needs of this specific population.<sup>98</sup> In order to do so, the UCSF CoE conducted a comparison study between the healthcare needs of Russian-speaking and English-speaking whites seeking care. 99 An unexpected finding was that Russian-speaking patients did not prefer linguistic matching with their providers but rather valued greater choice among English-speaking doctors with the assistance of translators. Services were subsequently modified to address the findings of this study.

Middle Eastern populations represent another significantly linguistically isolated population classified as white. Contrary to the findings of the UCSF Russian-speaking study, efforts undertaken at the University of Michigan CoE have identified the need for linguistic and cultural matching of providers to serve this population. The Middle Eastern Women's Health Clinic was designed to provide culturally competent gynecological care and primary care education and

outreach for women of Middle Eastern descent. The target audience is Arabic-speaking women seeking culturally appropriate care. The experiences of the UCSF and the Michigan CoE projects reinforce the need to understand the individual community and to remain cautious about generalizing from one linguistically isolated group to another.

The Boston University CoE has partnered with the Boston University Haitian Health Institute to develop programs specifically geared toward a community of women of African descent who are faced with additional barriers of language and literacy. The programs sponsored include development of videotape and radio educational materials to overcome the barriers of literacy and language, outreach for screening services, and service provision for women underinsured and uninsured. One project undertaken by the CoE was the development of an educational video to address Haitian women's attitudes and beliefs about breast cancer screening and, ultimately, to increase their use of mammography. The project responds to compelling evidence that Haitian women are more likely to die from breast cancer than their white counterparts. 100 The 15-minute video uses the expertise of Haitian American physicians at Boston University Medical Center to create culturally appropriate discussions of barriers to breast cancer screening in the community. The video is to be evaluated in educational sessions with lowincome Haitian women who have low breast cancer screening rates. Following the evaluation, the video is to be distributed by the American Cancer Society and used in Haitian American physician offices in Boston, New York, and Florida. In addition, the Haitian American Public Health Initiatives plans to include the video in its local cable television programming and promote it to Haitian American local access cable outlets nationwide.

In addition to these specific examples, all CoEs have undertaken translation of written materials into the native languages of the non-English-speaking populations served by each center. One of the broadest examples of this was undertaken by the Harvard University CoE, where the Learning Center at Beth Israel Deaconess Medical Center and the Women's Health Association at Massachusetts General Hospital developed and disseminated materials in Russian, Spanish, Por-

tuguese, Italian, Arabic, Vietnamese, Thai, Korean, Chinese, and Haitian Creole. The UCLA CoE, through the Iris Cantor-UCLA Women's Health Education and Resource Center, has undertaken a different approach. Rather than conducting its own translation, it has compiled, reviewed, and categorized available health education materials in languages other than English with information on where to obtain the materials and the cost (if any). The University of Washington developed the CARE-A-VAN project to offer culturally sensitive breast health education programs to medically underserved population, including non-English speaking women. The fully equipped outreach CARE-A-VAN travels to various locations and has a staff of approximately 40 multiethnic, bilingual volunteers. The program has obtained or developed educational materials in English, Spanish, Cambodian, Laotian, Mandarin Chinese, Korean, Vietnamese, Tagalog, and Russian.

## Addressing additional barriers to care

Other populations not defined by race, ethnicity, or non-English proficiency also are considered underserved by the healthcare system. Three areas of particular attention by CoEs have been age, sexual orientation, and disability status.

Age. Women at either end of the age spectrum (early adolescence and elderly women) are often excluded from services, and ageism often compounds the effects of gender, race, and SES.44 The needs of adolescent girls are acknowledged by all the CoEs, which have developed teen clinics, including school-based clinics, education programs, leadership development initiatives, and peer education programs. The University of Michigan CoE has developed a comprehensive Adolescent Health Program to provide a full range of adolescent-centered health services. The program was decided on through extensive partnering with teens, their parents and families, schools, the community, and several hospital departments. The target audience of the program is not only teens but those who interact with teens as well (teachers, healthcare providers). The program has published brochures explaining teens' rights to accessing healthcare services, confidentiality, and other issues related to adolescent healthcare. Educational programs and work-

shops are offered to teens, educators, providers, and parents.

Violence is increasingly recognized as an important factor in young women's health. The Indiana University CoE is developing a culturally appropriate and gender-specific education program that deals with domestic violence for adolescence. In addition to addressing specific needs, most of the CoEs recognize that the health needs of young women are the result of a complex interaction of individual, community, and social level factors that must be addressed long before a young girl is technically a teen. An example of such an approach is the Tulane/Xavier University CoE "Girls First" summer program for African American girls ages 9-13. Girls engage in movement exercises and sports, as well as educational activities, which promote their social, cognitive, and physical well-being.

At the other end of the age spectrum are the health needs of older women, which often have been ignored by women's health services. <sup>101</sup> As with most healthcare systems, the CoEs are all addressing the disease-specific needs of this population (i.e., breast cancer, osteoporosis, and cardiovascular disease), which tend to focus on the prevention aspects of these conditions by targeting women in the perimenopausal and early menopausal years. However, the needs of elderly women aged 70-plus are often ignored. Both the UCLA and the Wisconsin CoEs have moved beyond the traditional approach to develop comprehensive female-specific geriatric healthcare delivery programs.

Sexual orientation. Lesbians are another group where past and current discrimination plays a role in reduced healthcare access. 102-104 Lesbians, like other marginalized groups of women, underuse healthcare services and also seek healthcare later than do heterosexual women.<sup>105</sup> Fears of disclosure and provider homophobia have been shown to have an impact on the healthcare received by lesbians. 106 As a component of a multi-CoE collaborative project, focus groups with lesbians regarding healthcare delivery needs were held by the Boston University CoE. Subsequent to those, the Magee Women's Hospital CoE and the Pittsburgh Lambda Foundation supported five additional focus groups through the Epidemiologic Study of Health Risks in Lesbians (ESTHER). The findings of these groups have helped several CoEs develop activities related to

meeting the needs of this underserved population. The UCSF CoE is a cosponsor of the nation's first Lesbian Health Research Center, launched in July 1999.

Disabilties. Women with physical disabilities, despite the Americans with Disabilities Act, continue to experience physical barriers to reaching care and physical barriers at the site of care. The barrier most frequently cited by women with physical disabilities when having a pelvic examination was the difficulty in using the standard examination tables. 107 Although adjustable height examination tables are available to accommodate most physical limitations, few medical offices use them. 107 Women with disabilities have expressed frustration in obtaining mammograms because of the inaccessibility of the equipment, and women with physical limitations are less likely to receive preventive health services. 108-110 Several of the CoEs have fitted their clinical and mobile units to accommodate women with physical limitations. Also recognizing that disabilities affect women of all ages, the UCLA CoE supports the Mobilizing Choice sexual and reproductive health education program for youth with disabilities. The program consists of a 7week series on issues, such as family planning, reproductive healthcare, and STDs.

Deaf women represent another community that is often overlooked. 111 Language issues are central for the deaf population when access to American Sign Language interpreters may be difficult.112 Deaf persons participating in focus groups have articulated practical barriers to effective healthcare, including problems with scheduling appointments and communicating with providers. They believed that providers are ill prepared to care for them and expressed concern that prejudice might be a more subtle obstacle. 113 These issues are exacerbated for services such as mental health. 114 Researchers at the University of Pennsylvania CoE created an outreach program entitled "Did You See What She Said? Creating Access to Healthcare with Deaf Women." The goal of this program is to overcome healthcare barriers and optimize the use of visually accessible information pathways to empower deaf women as informed and effective consumers and advocates of healthcare services. The program seeks to provide training and support to deaf women, as well as to include deaf women in the training, advocacy, and technical assistance of healthcare systems, managed care organizations, and healthcare providers and institutions in making their services accessible to deaf women.

## Limitations of this analysis

There are several limitations to the analysis of the CoE efforts, including a narrow focus on meeting the clinical care needs of underserved women and reliance on race as a means of understanding health inequalities.

Limiting the focus to clinical care services. Research suggests that access to medical care plays a relatively minor role in explaining inequalities in health. 115,116 However, advocates for improved health argue that researchers should not be too quick to dismiss the role of access to and quality of medical care in addressing these disparities.<sup>33</sup> The introduction to the report Key Fats: Race, Ethnicity, and Medical Care explains, "While some would argue that economic and environmental factors are more important determinants of a population's health than medical care, the benefits of medical care in preventing and reducing the burden of illness, injury, disability and premature death are undeniable."75 Equality of access to medical care should continue to be an important and desirable goal and is critical to preventing further deterioration of health.<sup>17</sup> In fact, medical care appears to have a greater impact on the health status of lower-SES groups than on their higher-SES peers. Williams writes, "for disadvantaged groups faced with multiple vulnerabilities, medical care may be the only health-protective resource."17 Thus, it is important to continue to assess the role of medical care in addressing racial and ethnic differences in health.<sup>117</sup> The limitations of this approach, however, are recognized and provide support to other CoE activities that seek to address social inequities through leadership development among women from diverse backgrounds and participation in grass roots community-based activities seeking to tackle larger structural factors that contribute to health inequalities.

Reliance on race as a classification variable. The use of race as a categorization for health outcomes is not without criticism. As Smaje explains, "To consider race as if it is some essential quality attached to individuals is therefore to risk reifying as a matter of social being something that fundamen-

tally has to do with socio-structural forces that impinge upon people's lives."47 Lillie-Blanton and Laveist argue that "much of the published research on race/ethnicity and health reinforces the belief that health status is primarily a function of characteristics inherent to the individual his/her racial/ethnic group."38 Finally, LaVeist warns, "continuing to document race differences in health bolsters pseudo-scientific racist arguments about the existence of biological differences between what we call races and the genetic inferiority of certain race groups."49 Despite these words of caution, most researchers on disparities in health recommend continued attention to the role of race and ethnicity in health simply because of the central organizing feature of race in American society. 118 Williams provides three justifications for continued attention to the role of race in health: (1) the current racial categories capture an important part of inequality and injustice in American society, (2) racial categories have historically reflected racism, and (3) categorization into races has been consequential for every aspect of peoples' lives. 119 However, to truly understand the relationship between race and health, tools for measuring racism, migration, and acculturation as well as a comprehensive assessment of SES must be addressed central to the discussion. 120 Of particular concern to many investigators is the role of residential segregation<sup>13,23,121</sup> and the racialized nature of the healthcare system. 122-125

Researchers interested in the relationship between race and health argue that that there must be explicit incorporation of the role of racism as a central determinant of health status, as discrimination occurs at both the level of the individual and the level of the institutions within society. 42 Racism is operationally defined as beliefs, attitudes, institutional arrangements, and acts that tend to denigrate individuals and groups because of phenotypic characteristics or ethnic group affiliation. 126 The inclusion of work on institutional racism addresses the issue of effect and practice rather than intent<sup>127-130</sup> and helps to distinguish between the actions of individuals and the racial stratification resulting from structural impediments and processes.<sup>123</sup> In addition the role of perceived racism has been shown to be an important factor in health outcomes. 131-141 Perceived racism refers to the subjective experience of prejudice or discrimination and is, therefore, not limited to those experiences that can be viewed objectively as representing racism. 126 This

paper does not seek to address these concerns but recognizes the importance of this work. Future work by the CoEs should investigate the role that racism has in the provision of care and in the outcomes of patients receiving clinical care services through its programs.

#### **CONCLUSIONS**

Robert and House argue that "at this point, socioeconomic and related racial and gender differences in health are arguably the major public health problem."33 Race, class, gender, and other markers of power intersect to produce inequality. This paradigm provides an interpretaive framework for thinking how intersections of race, class, gender, and sexuality shape any group's experience across a specific social context.<sup>142</sup> Presented here are the experiences of the national CoEs in identifying the clinical care needs of underserved women as defined by this intersectionality. Central to the work is the capacity of each CoE to develop an organic approach to identifying and caring for underserved populations. The work presented does not address the fundamental question of whether more services actually reduce the disparities in health outcomes but rather recognizes that the role of medical care in improving health remains disputed. Instead, the CoE's operate under a framework of social justice until this dilemma is resolved. If women deserve gender-specific healthcare, attention must be paid to seeing that access to that care is not limited to certain groupings of women with greater privileged status within the American social system.

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